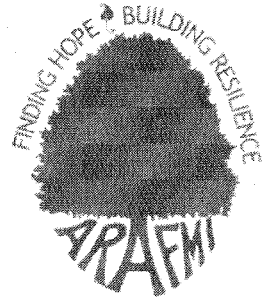


A.O.C. 7/7/08

Submission No. 578

(Inq into better support for carers)



Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on

Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am submitting to the Inquiry the following information gathered at a Carers forum held by Arafmi WA on Wednesday 25th June 2008. This forum was attended by approximately 15 family members and friends who are providing care and support to partners and siblings who have mental health issues. The following is a compilation of the participants response to these questions, the phrases in italics are direct quotations.

1. The role and contribution of carers in society

As a carer, I feel that my role is...

- *"To be the main support"*
- *"To be all things to everyone"*

The main issues that Carers mentioned in regards to their role were its invasive and all consuming nature. Associated with this was a loss of the Carer's identity and the repetitiveness of being a Carer,

- *"facing the same issues every day"*

2. The barriers to social and economic participation for carers

As a carer, I face the following problems ...

a) Lack of Financial Support

The area of financial support can be divided into two main areas –

- i. The lack of financial remuneration to Carers is a major barrier to social and economic participation.

- *Increase payments made to Carers, to adequately compensate them for their efforts and minimize the financial burden of caring.*

Carer's made the point that if they are to access in-home support they can pay in excess of \$17.00/hour, yet they are not compensated anywhere near this amount of money for the on-going care they provide. The lack of financial remuneration is seen by many as a devaluation of their role in supporting their family member. It was pointed out that the care by family members reduces the cost to government of providing either crisis or on-going care for that family member.

- *Carers play a crucial preventative role, which helps reduce hospital admissions and subsequently reduces the financial burden on the health system.*
- *Lack of validation/recognition of Carer role by health system and government bodies like Centrelink e.g. Centrelink forms are more geared towards physical disabilities, and fail to capture episodic nature of mental illness; carers pensions may get affected if carer is unwell and unable to provide usual level of care.*

ii. Lack of support and understanding from Authorities when Carers need to manage the finances of a family member when they become unwell.

- *Establishment of some form of "official recognition" of being a carer that can be activated ("turned on") when loved one is unwell.*

Carer's raised the difficulty they experienced when a family member became unwell and they were unable to deal with Government Departments, Utilities such as Water & Electricity Authorities and Telstra because their role was not recognised. This led to extreme frustration for Carers when a family member was living by themselves and had their power or telephone disconnected and the respective authorities would not accept the intervention of the family member who was the Carer.

b) Lack of Information –

This involved both lack of general information about particular diagnosis and also lack of specific information from Clinicians and Medical Staff.

i. Lack of General Information about particular diagnosis

Many Carers felt a sense of social isolation when a family member is first diagnosed with a mental illness. This isolation is compounded when hospital staff do not refer family members to organisations such as ARAFMI who can provide counselling and support for them.

Many Carers stated that it was a learning curve not only about the illness but also learning about where they could access support and assistance for themselves.

- *[it was a] learning curve – over time you learn how to best deal with situation*

ii. Lack of specific information and recognition from Health Professionals

Many Carers were excluded by Health Professionals when preparing treatment plans for the Consumer and the information provided by Carers about the person's illness was often discounted. This was strongly echoed by many people who attended the forum. Carers were adamant that they needed to be included in any treatment plans as they were the ones who provided on-going care and support to the individual.

Carers' found it particularly difficult when their child moved out of adolescence into adulthood. Often Health Professionals stopped communicating with family members because of confidentiality issues.

- *Inclusion of families in treatment plan and ongoing service provision to consumers.*
- *A critical period for parents is when their children cross over from adolescence to adulthood. Much disruption and confusion arises in relation to confidentiality issues in particular.*

c) Lack of Access to Suitable Housing

Lack of suitable housing for Consumers also posed a barrier for many Carers. Adult children who had a mental illness were often unable to access suitable housing resulting in aging parents having to provide accommodation and support to the person. There was also the concern of aging parents as to what would happen to their child once they were no longer able to provide housing and accommodation.

Carers' raised the fact that there are -

- *"limited resources available in relation to future planning"*

3. The practical measures required to better support carers

Many Carers' advised that they needed help with

- a) financial support – this point has already been raised
- b) long term options for support of their family member or friend. This support included accommodation which has been mentioned but also the provision of meaningful activities. There was recognition that some Consumers are not able hold down employment but there was still a need for meaningful activities that provided a structure and purpose. Many Carers' felt unable to access opportunities or exercise choice about what they wanted to do within the wider community because their family member was always at home.
 - *"the notion of work not just being goal driven, but an avenue of providing meaning and structure to one's life, so as to enhance mental health."*
- c) Accessing a suitable help line to have the opportunity of talking to people who have an understanding of the issues faced by Carers'. Carers spoke of the need to talk and debrief when their family member had become unwell and required police escort to be hospitalised. They also spoke of the need to speak to a person who understood the particular issues and strains that Carers experience.
 - *Establish a mental health Carer support line, where Carers can speak to knowledgeable individuals who have a good understanding of mental health issues and services.*

4. Strategies to assist carers to access opportunities and choices

I think the Government can better help carers by ...

The following is a compilation of the above mentioned points –

- a) Provide meaningful financial support for Carers that will enable them to engage with the wider community and exercise choice.
- b) Enacting policies that ensure Carer's are included in the Treatment Plans of family members. This may mean providing training to Health Professionals and Clinicians on the importance of family members and their role in the on-going care of the individual.
- c) Establishing a planned process and funding that will address the issues of long term support for family members where there are aging Carers.
- d) Provide a legally recognised way in which Carers can act on behalf of and represent a family member who has become unwell, for example with Centrelink, Telstra and other Government instrumentalities.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for carers in Australia.

Yours sincerely

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